

Office of Congressman Charles W. Dent
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Congressman Dent honors MPS Awareness Day, raising awareness for genetic diseases

U.S. Rep. Charlie Dent (PA-15) is asking all Americans to honor National MPS Awareness Day, Feb. 25, a day devoted to raising awareness for a group of seven often undiagnosed, genetic diseases known as Mucopolysaccharidoses, or MPS.

These genetic diseases are caused by enzyme deficiencies that prevent the body from breaking down and recycling materials in cells which can result in stunted growth, stiff joints, speech and hearing impairment, breathing problems, mental retardation and a dramatically shortened life span.

Congressman Dent is co-sponsor of legislation that would officially recognize the goals of National MPS Awareness Day to help better inform the public of these misunderstood diseases.

“Like so many Americans, I was unaware of MPS until it was brought to my attention first-hand,” Congressman Dent said. “In January of last year, one of my constituents, Les Sheaffer, came to talk to me about his daughter, Brittany, who has MPS III or Sanfilippo Syndrome. My staff and I were touched by Brittany's story and the Sheaffer family's resolve.”

The legislation to recognize the goals of National MPS Awareness Day, which was introduced by U.S. Rep. Ron Kind of Wisconsin, is pending

action in the House. The Senate passed its version of the legislation on February 16th.

“With early diagnosis, treatments can minimize potentially life-threatening complications and greatly improve the quality of life for these children and their families, who bravely face the devastating effects of MPS,” Congressman Dent said. “Unfortunately, MPS is not well understood in the medical community and as a result, diagnosis is often delayed. That's why we are raising awareness and supporting those who are seeking a cure.”

In a further effort to increase awareness, the National MPS Society today announced *Join the Search for Patients with MPS*, a nationwide pursuit to identify children with MPS. The Society is asking physicians involved in caring for children during their path to diagnosis to take a pledge to search for these patients and encourage their colleagues to do so as well. Physicians, parents and the public can get more information and join the search for patients with MPS by logging on to www.jointhesearch.org.

To commemorate this nationwide call for attention and diagnosis, patients, families and genetic experts from across the country will convene in New York City today (Feb. 24) to unveil a unique photo exhibit featuring individuals with MPS and preside over the closing bell ceremony at the NASDAQ Stock Market.

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